

CT General Assembly
Insurance & Real Estate Committee Public Hearing

February 3, 2015

Testimony in Support of SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections.

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee, my name is Paula Penna of Manchester, CT.

I am writing on behalf of Committee Bill #15, requiring insurance coverage for the diagnosis and treatment of PANDAS PANS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Strep).

My 17 year old daughter has been afflicted with this terrible disorder since age 10, and was misdiagnosed until age 15. We have been dismayed by the lack of insurance coverage for diagnosis and treatment, even on Cigna Open Access Plus. The medical costs to me, as a single working mom of 2 children, has literally destroyed our financial state at this point. We have lost our home, in fact, as a result. Children this ill NEED insurance coverage, and I feel the insurance companies need to take responsibility. My daughter's best option at this point is IVIG treatment. Cigna has denied us several times, and her doctors have been in peer review trying to get this treatment covered. In recent studies, IVIG shows an 82% efficacy rate for PANDAS. We were fortunate enough that a private donation of \$11,550 was given on my daughter's behalf, and covered ONE IVIG treatment out of the 12 that the doctor has ordered. With that single IVIG treatment, my daughter was 100% healthy for almost 5 months - for the first time in her life, she was not ill, did not require medical attention, and her immune system seemed to operate appropriately. Her PANDAS PANS symptoms were also 100% gone - it was the best 5 months of her life! However, due to the lack of insurance coverage, we have not been able to obtain another IVIG treatment. This is a shame because now my daughter is back to being sick often, has secondary infections, and her PANDAS PANS symptoms have returned - just as she is applying to colleges. We are back into having multiple doctor appointments, medications, time missed from school and work, siblings affected negatively by the stress, etc.

PANDAS PANS interrupts the child's life unexpectedly and destructively. It destroys families, creates PTSD in siblings (her younger sister suffers from PTSD, as is common in PANDAS families), and financially ruins the family. Our children deserve a future, and they deserve to get treatment for their medical condition just as much as a child with cancer, or MS, or another life-threatening illness. I do not believe insurance companies should be allowed to tell doctors how to care for their patients, or what is "medically necessary". In my daughter's case, all of her doctors (in separate practices and fields) feel that IVIG is her best option for a full recovery - immunologist, allergist, pediatrician, and psychiatrist, all in agreement. However, Cigna keeps refusing us, and we don't know where to turn at this point. It's a serious crisis, and nonsensical. The constant medical attention, lab services, doctors visits, medications, etc are costing the insurance company

a fortune AND the child is still sick; IVIG treatment can save my daughter and allow her to have a healthy adulthood, AND save the insurance company money in the long run. As I said, it is nonsensical. Add in the cost of special education services, and the state is spending money it NEED NOT SPEND, because there IS treatment for these children if only the families can afford it (insurance companies doing their part).

Please help this bill to pass. PANDAS children and their families implore you.

Thank you,

Paula Penna, MMed., BMus.

517 Hartford Road

Manchester, CT 06040